

## Summary of Themes/Issues from Public Comments on Vermont Services for People with Autism Spectrum Disorders

Act 35, An Act relating to Autism Spectrum Disorders, was passed by the legislature and signed by the Governor in mid-May, 2007. It directs the Vermont Agency of Human Services and the Department of Education to develop a plan for providing services for people with ASD across the lifespan and in their homes, schools and communities. The legislation requires the involvement of key stakeholders in the development of the plan. In response to this, the Agency of Human Services and the Department of Education have invited individuals with ASD, families, community providers and state officials to participate on committees to help develop this plan. About 85 stakeholders have been organized into a Steering Committee and five additional committees to work on developing components of this plan. The committees began meeting in August and have been hard at work developing recommendations for the state plan.

In addition to this, five forums were organized to gather additional input from the public on the direction the state should take in further developing services and supports for people with ASD. Forums were held between September 17 and October 4, 2007 in Montpelier, St. Johnsbury, Burlington, Rutland and Springfield. One hundred and ninety-five (195) people attended the forums. The attendees included individuals with autism spectrum disorders (ASD), family members of individuals with ASD, school personnel, community service providers, college and university staff, state government staff, legislators and reporters from the media. People who did not wish to speak were given the opportunity to provide written comments. The questions posed at the forums were also posted on-line for people to mail in comments as well. Fifty-seven people provided written comments.

The questions posed were:

What are your recommendations to the state of Vermont to move forward to enhance services and supports to people with ASD in:

- Schools, including post-secondary education
- Human services, including child and family support and adult services
- Medical services, including screening and diagnosis
- Coordination of services across systems

The spoken comments at the forums were recorded and transcribed. These were combined with the written comments into a forty nine page document that was reviewed by the Autism Planning Steering Committee. Using a template of themes and issues that emerged, the committee members tallied the frequency with which each theme or issue was mentioned within the transcript of comments. Sometimes people mentioned a broad category and sometimes more specific information under that category was noted. These were tallied separately. Below is a summary of the themes and issues that emerged from the public comments and the frequency with which they were mentioned.

People were also given an opportunity to rate their top three priorities for the state to develop and enhance services to individuals with ASD in VT. People filled out a form indicating their

choices from a list of 16 possible priorities. A report of their choices is attached to this document based upon whether they were a parent/family member or non-parent. Some people did not indicate their roles. The results are summarized below.

The input gathered from these forums and the work of the committees will be synthesized into a report that will go to the legislature in January, 2008.

**Themes from public comments:**

1) Access to screening and diagnosis - 14

Timely – 22

Sufficient number of trained evaluators (train more/pay more to attract) - 10

Accurate - 6

Periodic screening/re-evaluation at school – 1

**Total - 53**

2) Intensive early intervention services available - 20

Need for trained personnel, funding, programs developed - 5

Availability of home-based services for children not yet ready for classroom - 4

Address challenge of transition between FITP and EEE – 4

**Total - 33**

3) Need to listen to parents regarding the needs of their children as they know them best - 29

**Total – 29**

4) Training for all staff needed ( para-educators, Personal Care Assistants, teachers, job coaches, Department of Corrections staff, Agency of Human Services staff, nurses, etc) - 53

Enhance training of professionals in higher education – 10

Ongoing professional development for in-place professionals – 6

Ongoing staff supervision and support – 2

Prior to working with individuals with ASD - 1

Require certification in ASD – 1

Funding for training -1

Develop cadre of trained staff who would be available regionally to do training – 1

Effectiveness of training/implementation – 1

Technical assistance/mentoring/coaching – 1

**Total - 77**

5) Workforce development and retention - 2

Monetary incentives for attracting and retaining professionals, e.g. doctors,

OT, PT, SLP - 6

Recruit/develop professionals with expertise – 5

Livable wages for support staff - 2

**Total – 15**

6) Increase community awareness/education & acceptance - 8

First responders - 3

Students/classmates -1

Legal system – lawyers, police, judges, etc. – 1

**Total – 13**

7) Access to information and resources - 9

Regional autism centers - 8

Guidance/ technical assistance to schools to select appropriate interventions/strategies - 7

Coordination of information available - 6

Autism specialist in regions to support child/family in home, school and community – 1

**Total - 31**

8) Access to home/community services (non-school services) - 7

Adequate funding for services - 13

Funding for adults who are high functioning who need long term supports; expand eligibility criteria - 12

Expand system of care funding priorities in Developmental Services - 9

Comprehensive, wraparound services – 9

Increase availability of supports through Mental Health system – 7

Safety, resources, programs, tools, funding – 5

Clarify over who (Mental Health or Developmental Services system) should serve when there are multiple diagnoses; e.g. ASD & mental health diagnosis - 5

Developmental Services waiver for kids - 4

More counselors/therapists with ASD experience available– 4

Not a separate system of care for ASD - 3

Want a separate system of care - 2

Streamline application process for Medicaid, PCS, waiver – 2

Increase flexibility of Personal Care Services – 2

Responsiveness and continuity affected by overburdened case managers and turnover – 2

Mentorships – 1

**Total - 87**

9) Access to family support services- 13

Training available in how to support, teach and nurture child (including funding, child care to attend) – 16

Parent pressures (stress, care giving, level of support required) - 13

Peer navigator model – roadmap to navigate services - 8

Funding to keep families together (out of state custody or institutions) - 5

Advocates available to individuals and families – 4

Legal services, free mediation services available to families – 3

Aging caretakers - 2

Financial assistance 2

Taking family schedules into account (not 9-5) – 1

Phone line for family support – 1

Allow food stamps to be used for gluten free/casein free diet – 1

Family-centered attitude and approaches needed – 1  
Sibling stress - 1

**Total – 71**

10) Access to adult services - 4

Housing supports (group homes, assisted living, etc) - 9

Life skills & independent living skills training - 7

Peer support groups - 4

Maintenance of previously learned skills in adulthood - 4

**Total – 28**

11) Access to transition services - 7

Support for transition to adulthood - 10

Funding for programs focused on vocational/independent living like Vista, Threshold  
(three year residential training programs for young adults) - 5

High schools should focus on employment and independent living skills before  
graduation – 3

**Total - 25**

12) Access to employment supports - 7

Need for job coaches/job training – 13

More intensive services available through VR – 10

Education of business community about the assets and needs of people with ASD- 5

Resources/funding – 4

Post -secondary education, vocational technical education with accommodations - 4

Tie enhancements in employment supports to Governor's Next Generation initiative - 3

Incentives for employers to hire - 3

Livable wages for people with ASD – 2

**Total - 51**

13) Equity in access to services across state

Disparity of services across school districts/ human services in state - 10

Plan for Southern part of state – 2

**Total - 12**

14) Medical services

Training doctors on understanding ASD, screening and referral, associated illnesses and  
how to provide care - 27

Availability of doctors to be part of school team – 5

Insurance coverage for PT, OT, SLP - 5

Alternative/complementary medicine covered by insurance – 3

Thimerosal in vaccines - 3

Disseminate "Your Next Patient Has Autism" brochure – 3

Develop or recruit doctors available regionally who have expertise in meeting needs of  
individuals with ASD – 2

DAN (Defeat Autism Now!) doctors - 2

Insurance coverage for adults – 1

**Total - 51**

15) Increase accountability:

Perception that there is a lack of enforcement monitoring by DOE - 8

Lack of implementation of Individual Education Plans (IEP) - 6

Give DOE enforcement authority - 3

Collect more statewide data to assist planning – 3

Better accountability by schools through objective, measurable data on IEP goals – 1

**Total - 21**

16) Need for individualized services - 7

Lack of continuum of services for range of needs – 7

**Total - 14**

17) Provide options for education:

Creative, individualized programs in schools - 11

Availability of education funding for homeschoolers - 9

Specialized autism programs (e.g. Blue House, autism collaboratives) - 7

Consider pros and cons of inclusion vs. center-based services – 7

Inclusion with appropriate supports and accommodations – 5

Separate services – 3

Specialized support and oversight for para-educators – 1

Team of consultants available to high schools - 1

Private schools - 1

**Total – 45**

18) Education issues:

Parents to be treated as equal partners on teams – 7

Change “adverse effect” criteria for eligibility for special education - 7

Need small caseloads for intensive needs students - 6

Prevention of harassment/bullying - 6

Need for summer services - 5

Lack of appropriate services – 5

Recreate Autism Consultant position at DOE to consult on individual cases - 4

Recognition of needs of students with on high functioning end of spectrum – pragmatic language, social skills – 2

Provision of education by non-licensed staff (paraeducators) – 2

**Total – 44**

19) Access to recreational opportunities - 4

More summer camps (and funding to pay for) - 8

**Total – 12**

- 20) Coordination of services across systems/lifespan - 35  
Smooth transition between programs, grades, schools – 12  
Case management available across the lifespan to coordinate services – 7  
One case manager across school/human services 2  
State entity to oversee coordination - 2  
Education/human services under one administration – 1  
Coordinate eligibility criteria across education/ developmental services – 1  
Use FITP model of coordinated, family-centered approach -1

**Total - 61**

- 21) Range of interventions available - 4  
Social Skills support - 11  
RDI - 8  
Positive Behavior Supports (behavior as communication, non-punitive) - 5  
Support focused on needs of students with Asperger's – 5  
Natural therapies - 4  
TEACCH – 2  
ABA/DTL – 2  
OT, PT, SLP – 1  
Reading/math – 1  
Support for non-verbal students – 1  
Evidence based practices – 1  
Evidence based practices, unless alternative practices have a proven effective history with an individual – 1  
Inclusion practices – 1  
Facilitated Communication – 1

**Total – 48**

- 22) Social isolation/lack of friends for person with ASD - 4

**Total - 4**

## **Summary**

Some of the most frequently mentioned issues at the public forums include: access to timely and accurate diagnosis; training for all staff who work with individuals with ASD; access to a variety of home and community supports; family support; employment support; training for physicians on understanding ASD, screening and referral, associated illnesses and how to provide care and various other medical issues; need for a range of educational options and other educational issues; coordination of services across systems and the lifespan; and having a range of interventions available.

When asked to rank their top three priorities for the state in developing a plan for services for people with ASD, **parents** selected (see attached document for full report):

1. Enhance strategies for recruitment, training, support, accreditation and retention of workers who provide direct support to people with ASD and their families, e.g. personal care assistants, respite workers, para-educators, job coaches, etc.
2. Develop accessible locations for accessing information regarding diagnosis, options for treatment and intervention, available resources, family support, etc., such as regional autism centers.
3. Enhance vocational support system to increase successful employment of individuals of ASD.

The top three priorities selected by **non-parents** were:

1. Expand the availability of training in effective practices to schools, community agencies, specialists, medical professionals, consultants, family support workers, families, etc.
2. Develop accessible locations for accessing information regarding diagnosis, options for treatment and intervention, available resources, family support, etc., such as regional autism centers.
3. Tied for 3<sup>rd</sup>:

Increase access to timely screening, evaluation and diagnosis by standardizing the process and increasing the availability of professionals trained to diagnosis. AND

Enhance strategies for recruitment, training, support, accreditation and retention of workers who provide direct support to people with ASD and their families, e.g. personal care assistants, respite workers, para-educators, job coaches etc.

Top three choices for **all respondents**:

1. Expand the availability of training in effective practices to schools, community agencies, specialists, medical professionals, consultants, family support workers, families, etc.
2. Tied for 2<sup>nd</sup>:

Develop accessible locations for accessing information regarding diagnosis, options for treatment and intervention, available resources, family support, etc., such as regional autism centers. AND

Enhance strategies for recruitment, training, support, accreditation and retention of workers who provide direct support to people with ASD and their families, e.g. personal care assistants, respite workers, para-educators, job coaches etc.